Disability Visibility Podcast

Episode 11: Crip Aging and Crip Bodies

Guests: Patty Berne and Leroy Moore

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE WONG: Hello dear listener, my name is Alice Wong and I'm host of the Disability Visibility Podcast, conversations on disability politics, culture, and media. Today's episode is titled Crip Bodies and Crip Aging. My guests are Patty Berne and Leroy Moore, two people who have a lot of wisdom to share about their bodies and aging.

You might wonder why I'm using the word 'crip' in the title of this episode. I know that there are many people, both disabled and non-disabled, who are uncomfortable with it. I'm using it deliberately today because there is something culturally specific about celebrating disabled bodies that's rooted in pride and in direct opposition to the forces that tell us that our bodies are not enough. To crip something is to imbue it with disability culture. The way we age is different. The way our bodies change and move through the world is different.

So...let's talk about disabled bodies, self-love, and aging. How do we listen, honor, and treat our bodies? How do we value and treasure the elders in our communities? Patty, Leroy, and I explore this and more.

Are you ready? [electronic beeping] Away we go!

ELECTRONIC VOICE: 5, 4, 3, 2, 1!

Patty Berne Introduction

ALICE: So, Patty, thank you so much for joining me today.

PATTY BERNE: Thank you, Alice, for having me here.

My name is Patty Berne, and I am the Director of Sins Invalid, which is a disability justice-based performance project led by disabled people of color and queer and gender non-conforming people with disabilities. You know, I've been involved in disability-related organizing for maybe the last 15 years. Prior to that, I had been doing work in racial justice and gender justice movements, particularly working to end rape and sexual violence amongst women of color organizations. And this year, I celebrated my 50th birthday, which feels really good.

ALICE: Happy 50th birthday. That is a big milestone!

PATTY: I had a big banner at my party that said, "Still here. Still revolutionary."

Aging as a woman with a disability and coming to love your body

ALICE: How is your body right now, and how has the last few years been like for you in terms of aging and disability-related stuff?

PATTY: As women, as we age, as people with disabilities, neither are discussed in broader discourse, and it's as though older women don't exist in many ways except as kind of neutered objects. And that's the same way that people with disabilities are perceived: As neutered objects. Many people are surprised about seeing people with disabilities and our bodies as complex, whole beings, including our sexualities at any age. I really dig my body. I love my body.

A few years ago, I was like "What's going on?! I can't stand it. I'm old now!" And then I started to balance that ageism and the framing that I have to be less vibrant. It's not easy to contradict capitalism and media messages. So, I feel like it's still a process.

ALICE: Yeah, it's a continual process, but how did you get to the point where you truly love your body?

PATTY: When I was younger, I was really unhappy in my skin. I loathed my body when I was younger. Absolutely loathed being in my body, and it's still painful. My body is part of me, you know? I mean, there's no one thing. There wasn't a....

ALICE: There's no aha moment.

PATTY: Exactly! Exactly. There was no one.

ALICE: It's not like a movie where everything magically happens in one moment!

PATTY: Right. Not at all. It was a really long process for me. I was in therapy for most of my adult life and still do go intermittently. Things that were helpful for me were putting up pictures of myself as a child and really honoring little Patty, having little altars to different ages of myself where I was wounded.

I write love letters to myself. I would take myself out on dates. I would treat myself the way that I treated a friend that I had betrayed. Like, I apologized to my body for not loving it. I thanked my body a lot.

[mellow keyboard music]

It was really one day just recognizing what a sweet, hard-working body I have. I mean, it has done everything I have asked to the best of its capacity. I couldn't have asked for more. And it just, for so many years, I didn't listen to it, and I just would make demands on it. I notice all these cute little quirks about my body and myself now [chuckles], and yeah, it's just super cute and sweet, and I love it. I love myself.

Part of that--I'm sure you can talk to this, Alice--part of that is just growing older and being more comfortable with who we are and feeling good about what we can do.

ALICE: So, what are some of your advice for people on how to really listen to their bodies and taking care of their bodies and spirits?

PATTY: I mean, I can only speak for myself and what was helpful for me. I believe that when we're born, we are fully aware of our beauty and power and that our relationships with ourself, our bodies get severed. Lots of things can do that: Violence--be it family violence or medical violence--messages from the world, from media, and the magazines. Demonstrating to my body, well, I'll take good care of it. I'm not gonna let it get hurt. I'm not gonna deride it. Just like I would any friend, I would demonstrate that I love them, and I would tell them that I love them. So, I tell my body all the time how beautiful it is. I started with just making friends.

I guess if I could give any advice to people, I would say be gentle, the way we're wanna be with any friend. Be gentle and tender, and make sure you are your friend.

ALICE: Yeah. I think part of any kind of close relationship, whether it's with a friend or with your own body itself, requires intimacy and trust and vulnerability. Sometimes we don't even give ourself permission to surrender and just fully be engulfed with our feelings.

PATTY: Yeah, yeah. I agree 10,000%. It's hard to do your body justice when the world is telling us not to! And the world is telling us that oh, that body is better and deserves fairness and justice, and this body doesn't deserve that. You know, that's bullshit.

[low-key piano music]

Disability justice, collective access, and interdependence

ALICE: Two of the principles of disability justice is collective access and interdependence. How do you see these principles play out in your life as you age and with all the communities that you're a part of?

PATTY: To me, collective access means that we all have needs, and we can share those needs with each other without feeling shame. An example of that is when I'm working with attendants, they're there to help my body and to help me. But they have needs too [chuckles]. They're human beings. My body needs more assistance than theirs. That's reality. But it's also reality that it might get hot because I keep it real hot in the house, or they might need a drink. And so, I check in a lot. So, making sure people are fed and hydrated or whatever it is.

How can I make sure that even in the process of meeting my needs, somebody else's needs are not getting neglected? So, that's just one example of collective access that's like a personal, individual example. The process of meeting each other's access needs is interdependence, where we lean on each other to do that.

Our bodies, yes, they're distinct from each other, but we're also energetic fields. And when I'm around somebody, their energetic field is gonna influence me and vice versa. We're always in conversation, our bodies. We read each other's body language all the time, our tones of voice, the ways that we're moving or not moving. And so, whether or not we wanna acknowledge it, we're already interdependent.

Surviving ableism

ALICE: Absolutely. Is there anything else you'd like to share with me about crip aging and crip bodies?

PATTY: Politically, it's a miracle to survive ableism, and physically it's a miracle to survive all the labor that it takes to live in a body with impairments. So, more power to us [laughs]. More power to all the people [laughs] and especially older people with disabilities that are also facing white supremacy, gender-based oppression, immigration-based oppression or economic oppression,

exploitation. I mean, all of it, you know? All the things that are trying to stop us from living. I'm blessed to be able to live and continue what gives me passion and love. We're a rare breed [laughs]!

ALICE: I think, as you and I've seen in our community, there aren't that many elders. I feel like every disabled elder I know, we should shower them with gold medals. Because sometimes people don't realize it's a huge feat just to be where we are and just to survive and to exist. It's like we really should celebrate and honor the people who are with us.

PATTY: Oh my god, yes! Yes, yes, and yes!

ALICE: Well, Patty, you are a treasure. You really are a treasure, and this conversation is a treasure.

Finding Patty online

For people who wanna reach you or learn more about you, what are some ways they can find out more?

PATTY: Well, my work is with Sins Invalid. So, people can look on Facebook or our webpage or YouTube. And it's Sins Invalid. People can drop me a line at PattyBerne@SinsInvalid.org. I really do welcome conversation about this intertwining of experiences with disability and aging because neither are given the space to be honored in this U.S. cultural construct, in this little world [chuckles] of the U.S. And I want to help co-create that space with people.

And also, if people wanna see others doing it, the last Sins Invalid performance was entitled *Birthing, Dying, Becoming Crip Wisdom*, and we developed a lot of awesome material. We have lots of snippets available, and if people wanna look for those, that's Birthing, Dying, Becoming Crip Wisdom, a great performance.

ALICE: All right. Well, thank you so much for joining with me.

PATTY: Alice, you are so wonderful!

[low-key piano music]

Leroy Moore Introduction

ALICE: So, Leroy, thank you so much for talking with me today. Tell me a little bit about yourself and what you do.

LEROY MOORE: OK. So, I'm Leroy Moore. I do activism around police brutality against people with disabilities. I'm also a journalist. I write for the Bay View Newspaper. It's the only Black newspaper in the Bay Area. I also write for POOR Magazine. I'm also a lecturer. I've been on the college lecture circuit since '98 around race and disability. And also, an author of two books now: One book of poetry and a new book that just came out, a children's book.

ALICE: So, you have a big event coming up. You are gonna turn 50 soon.

LEROY: Yeah! The big Five Oh [chuckles]!

How you're feeling reaching the milestone of 50 years old

ALICE: Tell me about how you're feeling and what you feel like in terms of getting to this great milestone.

LEROY: Yeah, turning 50 with cerebral palsy, me and my friend Patty Berne had a joke: It's almost like dog years, you know? Because I think people with physical disabilities, once they age, it goes on so quickly and so sharply. When I hit 40, it's like almost hitting a wall. Your body just can't deal with all the pressure. The body just wears down.

I think for me, I had to really reshape the work I do and how I do it and what kind of energies that I put into it. And other projects or other things that come my way, I really have to be choosey. It's like, OK, I'll take this one; I won't take that one. So, yeah, becoming 50, it's beautiful in a way because I've been down certain roads in my life that I know now that I don't wanna go back down. So, I can easily check off [laughs] the list that I wanna do, just from personal experience. So, that's the good side of it. The other side of it is like, your body just can't do what you used to do, you know?

ALICE: Yeah. It is a huge achievement just to survive and get to the ages that we are. I don't think that's really valued or celebrated, and our culture doesn't appreciate the wisdom of our elders. What are your thoughts about aging and disability?

Our elders with disabilities

LEROY: Yeah. I think in this society, in this world we live in, capitalism don't really take into account of our elders. It's such a shame. When I was younger, in my teens and 20s, I used to work at this summer camp for people with disabilities, and every session was different. The last session was elder, and I had a really good chance. I had a chance in my life when I was younger to really sit down and listen to older people that had CP, you know?

And now, I look back on it. It's like, wow. Those times was like gold. Because I think we don't take the time, especially now, with the Internet, we don't really take the time to really listen to our elders and take in that knowledge. It seems like we always go around in circles because we don't really listen to our elders.

[pensive piano music]

ALICE: Who are the elders in your life right now?

LEROY: Beverly Jackson is the first Black disabled woman that I had a chance to work with when I was younger. She was running what's called UCP, United Cerebral Palsy. I'm gonna go see her hopefully in the Springtime. She's one of my mentors and one of my elders. Kiilu Nyasha, she's local in the Bay Area. She's a Black disabled activist that's been an activist since day one. She's an ex-Black Panther. She has a public access TV show now. She's one of my elders that I look up to.

Leroy's relationship to his body changing over time

ALICE: Great. So, can you tell me a little bit about how your relationship with your body's changed over time?

LEROY: Oh my god [chuckles]! Oh, Alice. Oh god. You know, of course, when I was younger, in my 20s and teenage years, I was doing sports, and I was working full-time. I didn't look at my body as being "different." It was just my body, you know? And now, as I get older, as I hit 50, whew! God. You know, when I was younger, I was like, aw, forget you. Come on. Let's do it [chuckles]. And now, I really listen to it. I really cherish it.

[light piano music]

ALICE: And do you think that having a disability your whole life is gonna help you in terms of adjusting to the aging process?

LEROY: I think having a disability, yeah, it really taught me to really look at my community first and really to test my community about who's really in my community, who's really down with me. Because having CP, you can't hide it, you know? You can't pass. So, it really taught me who's really my friends. Because you have to be really up front to deal with a person with CP. So, when I was younger, it really was black and white for me. Yeah, people had to really step up. And nowadays, my body tests the environment that I live in: Walking down a curb cut or walking down stairs. I really say, "OK. Let me do this do this way, or let me go over here. Let me take the ramp instead of taking the stairs." So, my body at age 50 really communicates with the physical environment, you know?

ALICE: What do you do now to take care of your body and giving it the love and respect that it deserves? What do you do to make yourself feel good and live well?

LEROY: Oh, well, I really eat better these days [chuckles]. Of course, when you're younger, you eat a lot of food fast and stuff. Yeah, I cut that out years ago. I just can't deal with that, you know? I used to be on 10 Boards of non-profits. I used to go here and go over there. And now I just really be selective about that. I turned down one of my college gigs. I've been on the lecture circuit since '98. I turned down one last year because it was back-to-back from another college gig. So, it was like I was going to New York, come back home for one day, and go right out again. That is the first time that I really listened to my body and to the stress that that would take, coming home, then packing up, then leaving again. I live on SSI. So, it's not like oh, I just turned down a gig. I turned down income. Being aware that my body could not do that, and really sticking with it instead of pushing it, that was a huge change for me.

I take a lot of hot showers. That really helps. Sometimes I take a hot tub, and that really, really helps. That brings me back to my youth because when I was in the hospital, doctors used to put people with CP in hot tubs because they said that that relaxes the muscles. So, I do that once in a while, and that's really good.

[upbeat, jazzy piano music]

And my mode of transportation is my three-wheel bike. I travel with my three-wheel bike all over the Bay Area. There's a step that's low to the ground so it's easy to get on. There's a wheel in front, and there's two wheels in the back. And there's this huge basket in the back. I like having a big, big seat, like a couch seat [chuckles]. So, it's big and soft. I think this last month, I had four flats in one month, and that totally destroyed my whole month. 'Cause like I said, my bike is my car. So, having those four flats really put me inside for almost a month. So, yeah, that tells you how important my bike is to my transportation and getting outside.

Valuing crip lives

ALICE: Is there anything else you'd like to talk about in terms of thinking about crip bodies and crip aging and what that means for you going forward?

LEROY: You know, at this time, with all of the natural disasters going around, hurricanes and earthquakes, and I'm very worried about people with disabilities, our elders in natural disasters and emergencies, you know? We are the last ones to be rescued. So, that's heavily on my mind.

ALICE: Yes, and so many of us are in institutions or hospitals where people get trapped. And like you said, it's really sad that we're often the ones left behind.

LEROY: Yeah, I mean, we saw that in Katrina in New Orleans. We're seeing that in Puerto Rico. We're seeing that in New Mexico. And living in the Bay Area, we also think about earthquakes. It's hard to say. It's just mind-blowing how elderly people and people with disabilities in natural disasters are just left behind.

ALICE: Yep. It says a lot about how people value us.

LEROY: Yeah, definitely. Definitely.

ALICE: Well, thank you so much for talking with me today, Leroy.

LEROY: Yeah, thank you, Alice!

Wrap-up

ALICE: This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast. You'll find links to organizations that Patty and Leroy mentioned on our website.

The audio producer for this episode is Cheryl Green. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

If you enjoyed the episode tell all your friends about it. You can also support the work of creating disabled media at our patreon page at Patreon.com/DVP.

Thanks for listening and see ya on the Internets! Byeeeee!

♪ Lord knows where I'm heading

It's hard out here for a gimp ♪